

Presentation
by
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Good morning. Let me begin by thanking The Los Angeles County Community and Senior Services and the City of Los Angeles Department of Aging for giving me the opportunity to provide input at this important forum. I'm honored to be among such distinguished colleagues in the field of aging. I am Donna Benton, Director of the Los Angeles Caregiver Resource Center.

The Los Angeles Caregiver Resource Center is one of 11 caregiver resource centers throughout the state of California. The Caregiver Resource Center system was the first state funded program in the nation to address the impact of chronic brain disorders on families. It was started 20 years ago by families of adults with brain impairing conditions such as Alzheimer's Disease, Parkinson's Disease and Traumatic Brain Injury. This consumer-directed systems mission is to help families and communities master the challenges of caring for someone with a brain impairment. It's a system which values collaboration, respect, choice and quality service delivery. The Centers offer comprehensive services designed to assist caregivers.

This brings me to the heart of what I want to discuss, the substantial role informal caregivers play in the health and long term care system. Let me illustrate this with a case example.

“Ms. J is a caregiver in Southern California. Her mother was diagnosed with Alzheimer's disease and her father cared for her until he, too, became ill. Ms. J moved in to care for both of her parents until her father passed away. Ms. J is 45 and has been residing with and providing care for her mother for a year. The demands on Ms. J are substantial---she initially needed to take a three-month unpaid leave of absence from her job. When her leave ended she resigned, still providing full-time care. She gave up her salary and her pension. In this regard, she says, “I'm giving up my financial future that I've been working towards”. In addition to these losses, she no longer has health insurance. She cites that as one of the major challenges she's facing. She has two children in college and one of those children was also on her health plan. Currently, both Ms. J. and her child are uninsured.”¹

Caregiving is a major part of the American family experience. The majority of adults- 80%- rely exclusively on family and friends to provide assistance. Nearly 1 out of every 4 households is caring for someone over the age of 50. Moreover, nearly 5 million informal caregivers provide care for someone with dementia.

Ms. J case is not atypical. Beside the financial toll, research has shown that providing care to older people and those with disabilities often exacts a heavy emotional and physical toll, even while it is a source of great personal satisfaction. Family caregivers face multiple competing demands for eldercare, childcare and work. The juggling act often leads to high rates of depression, as well as, increased risk for heart disease, hypertension and mortality among caregivers.

In a policy brief by Pamela Doty, she makes the following insightful observation:

“Family caregivers provide care holistically; this is, typically they try to provide whatever types of assistance their elderly or disable relatives need to be able to reside at home in safety, comfort and dignity...Family members do not refuse to meet a need because it is not in their job description or is not a covered service...”²

In California, we can thank the 3.2 million caregivers, (approximately, one-third of whom would reside in Los Angeles) for the conservatively estimated \$30 billion savings to our budget each year, because of their unpaid labor. But, we must do more for caregivers. Currently, health care planners and policies overlook this group. We cannot afford to neglect caregivers, because our health and long-term system will collapse when caregivers begin to wear-out.

There are some recommendations that have been put forth by family caregiver advocates, which I suggest we pay attention to as we create policies in the future.

1. Family caregiving concerns must be a key component of health care, long-term care, and social service policy making. In a nation that wants to encourage “family values”, we must value the family.
2. Family caregivers must be protected against the financial, physical and emotional consequences of caregiving that put their own health and well-being in jeopardy. If we ignore caregivers, we will only add people to our over-extended health care system.
3. Family caregivers must have access to affordable, high quality respite care as a part of the supportive services network. Respite helps sustain and re-charge caregivers.
4. Family caregivers should have consumer-directed choices to financing and delivering home care that complements unpaid family care. Family caregivers in consumer-directed programs report greater well-being than those receiving traditional services.
5. Family caregivers need support for family-friendly workplace policies. Flex-time, job, sharing, and information and referral to community services are only a few examples of support type services.
6. Family caregivers need assurance that there will be an affordable, well-qualified health care workforce now and in the future. We are facing a predicted shortage of health care workers, so it is critical that we include caregivers in the discussions about this problems

7. Finally, family caregivers need regular comprehensive assessments of their caregiving situation, to understand what help they require. It cannot be assumed that family members can always provide care. Nor should uncompensated care be considered in allocating long-term care benefits. Assessments of the family caregivers strengths, needs and preferences must be the foundation for a care plan.

Let me end with the reminder that in Los Angeles we must always address issues of diversity. Diversity as it is reflected in the various cultures, ethnicities, lifestyles, languages, education levels, economic spectrums and ages of our communities. When we address caregiver needs, we must integrate the preferences of these diverse communities in our policies and programs.

Yes, there is diversity among caregivers, but most subscribe to the belief that, “There’s no place like home”. Thank you

References

1. Lynn Friss Feinberg & Sandra Newman. Family Caregiving and Long-Term Care: a Crucial Issues for America’s Families, Policy brief June 2004. Family Caregiver Alliance, National Center on Caregiving
2. Pamela Doty. Consumer-Directed Home Care: Effects on Family Caregivers, Policy brief October 2004 Family Caregiver Alliance, National Center on Caregiving
3. National Alliance for Caregiving. Family Caregiving and Public Policy: Principles for Change December 2003. <http://www.caregiving.org/principles.htm>